

EVALUATION DATA COLLECTION PROCEDURES

This document describes the shared care planning evaluation procedures for local health departments (LHDs).

OCCYSHN is conducting a formative evaluation of LHDs' implementation of shared care planning. A formative evaluation seeks to help develop (or form) a program; the intention is to identify areas for program improvement (Rossi, Lipsey, & Freeman, 2004). The evaluation protocol has been approved by Oregon Health & Science University's (OHSU) Institutional Review Board (IRB) and involves three data collections:

- Shared Care Plan Information Form (SIF)
- LHD Shared Care Planning End of Year Report
- Shared Care Planning Family Survey

All data are collected through a HIPAA compliant, secure web application for online surveys, called REDCap. The following sections describe the procedures for each data collection. If you have any questions about the shared care planning evaluation procedures, please contact OCCYSHN's Assessment & Evaluation unit.

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SHARED CARE PLAN INFORMATION FORM (SIF)

Following the creation or re-evaluation of each shared care plan, LHD staff will complete a short form, the Shared Care Plan Information Form (SIF), online via REDCap. OCCYSHN will use these data to track the number of new care plans developed, the number of existing care plans re-evaluated, the number of care plans that serve transition-aged youth (12 years old up to their 21st birthday), the number of care plans for transition-aged youth that included transition goals, and the number of children served. The results will be used (a) for required Federal Title V Block Grant reporting, (b) to monitor LHD progress in completing their required shared care plans, and (c) to describe elements of the shared care planning process. For your reference, a copy of the SIF is attached to this document.

The procedures for completing each SIF follow.

1. Every month, OCCYSHN will send the SIF web link to all LHD shared care planning participants who are recorded in our database.
 - This web link will always be the same. The purpose for sending the link to you monthly is so that you will have easy access to the SIF.
 - If there are other LHD staff developing shared care plans, please share this web link with those staff.
 - A new Shared Care Plan Information Form (SIF) may be accessed any time through this web link.
2. Following the creation or re-evaluation of each shared care plan, LHD staff will click on the web link to complete the SIF.
 - LHD staff should enter the child or young adult's initials and date of birth, the date that the shared care plan was created and/or re-evaluated, and other required information into the SIF.
3. The SIF consists of 2 pages. At the end of each page there is a submit button. After completing the first page, click the first submit button.
 - Depending on your responses to the first page, you will then be taken to either questions about a new child care plan, child care plan re-evaluation, new young adult care plan, or young adult care plan re-evaluation.
 - The second submit button will transmit the completed SIF to us.
4. If you would like to receive an email notifying you that the SIF was successfully submitted, you can enter your email address into REDCap after you complete the entire form. A notification email will be sent to you.
5. If you would like to print out a copy of your completed SIF, you will be able to print out a copy of the SIF after completing each page. There is a "Download" button after each page of the SIF. Clicking this button will download your SIF as a PDF, in which you can print out.

Other Important SIF Information:

- We will not link re-evaluations conducted in the 2018-2019 and 2017-2018 contract years with shared care plans initiated in the 2016-2017 contract year. During 2016-2017, we sought to avoid collecting personal health information (PHI). The SIF collects the child/young adult's initials and date of birth. If your data are entered accurately, it will enable us to track re-evaluations of shared care plans within and across contract year 2 (2017-2018) and year 3 (2018-2019).

LHD SHARED CARE PLANNING END OF YEAR REPORT

LHD staff will complete this end of year report online via REDCap. The purpose of this report is to describe the shared care planning implementation process in detail including communication methods, service gaps and redundancies, barriers, and infrastructure developed to support shared care planning. LHDs participating in the OCCYSHN grants will be asked additional questions about their experience engaging primary care and/or developing or supporting standing teams for shared care planning.

1. On *September 15, 2019*, OCCYSHN will email the shared care planning lead, identified by each LHD, a unique web link to complete the end of year report. This is a unique web link to track responses, and should not be forwarded to others.
 - Multiple staff may provide input into the report. For example, if multiple LHD staff members are involved in the shared care planning process, these staff may discuss report questions as a group.
 - Responses may be prepared outside of the online survey (e.g., in MS Word) and then copied and pasted into REDCap for submission by recipient of the web link. We will email a copy of the questions to your shared care planning lead.
2. The shared care planning lead will submit the LHD's report. OCCYSHN expects the end of year report to be completed by *November 5, 2019*.

SHARED CARE PLANNING FAMILY SURVEY - STUDY INTEREST FORM

OCCYSHN will collect data about family experience with the shared care planning process through an online and paper survey entitled, "Experiences Working with Your Child's Health and Other Care Professionals." Both the online and paper formats of the survey will be available in English and Spanish. LHD staff will ask families if they are interested in participating in this survey data collection using the attached Study Interest Form, which is also available in both English and Spanish. Families will receive a \$25 prepaid vendor card for participating in the survey. For your reference, a copy of the Study Interest Form and Family Survey are attached to this document. The procedures for asking families if they are interested in participating in the survey, including OCCYSHN's administration procedures, follow.

1. During the initial contact with the family, LHD staff will introduce the family survey opportunity. LHDs will let families know that they will be asked about their interest in participating in a survey at the end of the shared care planning meeting.
2. LHD staff will print the Study Interest Form and bring the form with them to the initial shared care planning meeting.
3. LHD staff will read the Study Interest Form to the parent/guardian after developing the shared care plan for their child and ask if they are interested in participating in the survey.

4. If the parent/guardian is interested in participating, LHD staff will complete the Study Interest Form with the parent/guardian.
5. LHD staff will then submit the completed Study Interest Form to OCCYSHN via secured fax.
 - OCCYSHN's fax number is 503-494-2755.
6. Two to four months following the creation of a child's shared care plan, OCCYSHN will email a unique web link to the survey via REDCap or mail a paper survey to parents/guardians who reported interest in participating in the survey.
 - Enclosed with the paper survey will be a prepaid stamped return envelope.

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OCCYSHN requires that the following set of questions be completed for each shared care plan created or re-evaluated. OCCYSHN will use the results of this data collection to track local health departments' completion for Federal grant reporting purposes and to describe elements of the shared care planning process.

If you have questions about this data collection, please contact Alison Martin, PhD, OCCYSHN Assessment & Evaluation Coordinator, 503-494-5435, martial@ohsu.edu or Sheryl Gallarde-Kim, MSc, OCCYSHN Assessment & Evaluation Research Associate, 503-494-2723, gallarde@ohsu.edu.

Thank you!

1. What county is your local health department located in? *(Please check one response.)*

- | | |
|-------------------------------------|--|
| ☐ Baker | ☐ Lake |
| ☐ Benton | ☐ Lane |
| ☐ Clackamas | ☐ Lincoln |
| ☐ Clatsop | ☐ Linn |
| ☐ Columbia | ☐ Malheur |
| ☐ Coos | ☐ Marion |
| ☐ Crook | ☐ Morrow |
| ☐ Curry | ☐ Multnomah |
| ☐ Deschutes | ☐ North Central (Wasco-Gilliam-Sherman) |
| ☐ Douglas | ☐ Polk |
| ☐ Grant | ☐ Tillamook |
| ☐ Harney | ☐ Umatilla |
| ☐ Hood River | ☐ Union |
| ☐ Jackson | ☐ Wallowa |
| ☐ Jefferson | ☐ Washington |
| ☐ Josephine | ☐ Wheeler |
| ☐ Klamath | ☐ Yamhill |

2. What are the initials of the child or young adult for whom you are reporting? *(Please enter one letter in each space.)*

First Middle Last

3. What is the date of birth for this child or young adult? *(Please type the date in the space below using mm/dd/yyyy format.)*

____ / ____ / ____

4. What is your first name? *(Please type the name of the person entering the data in the space below.)*

5. What is your last name? (Please type the name of the person entering the data in the space below.)

6. Did you facilitate the shared care planning meeting? (Please check one response.)

- ☐ Yes → SKIP to Question 9
- ☐ No, another LHD employee facilitated the meeting → Continue to Question 7
- ☐ No, the shared care planning meeting was part of an IEP/IFSP, Wraparound, or other meeting → SKIP to Question 9

7. What is the name of the local health department staff person who facilitated the shared care planning meeting? (Please type the person's first and last names in the space below.)

8. Does the person work for your local public health department? (Please check one response.)

- ☐ Yes
- ☐ No

9. To the best of your knowledge, what type(s) of conditions does the child or young adult have? (Please check one for each.)

Condition	Yes	No	I don't know
a. Medical (e.g., cystic fibrosis, muscular dystrophy, seizures, etc.)	☐	☐	☐
b. Behavioral/mental (e.g., ADHD, anxiety, depression, substance abuse, etc.)	☐	☐	☐
c. Developmental (e.g., autism spectrum disorder, developmental delay, etc.)	☐	☐	☐
d. Social complexity (e.g., domestic violence, food insecurity, homelessness or housing instability, joblessness or underemployed, parental incarceration, parental mental health conditions, etc.)	☐	☐	☐
e. Other, please specify:	☐	☐	☐

10. Are you reporting about a shared care plan for a child or young adult? (Please check one response.)

- ☐ CHILD: Less 12 years old → *Continue to Question 11*
- ☐ YOUNG ADULT: 12 years old up to the child's 21st birthday → *SKIP to Question 27*

11. Are you reporting the initiation of a new shared care plan or the re-evaluation of an existing shared care plan? (Please check one response.)

- ☐ New → *Continue to Question 12*
- ☐ Re-evaluation → *Skip to Question 44*

Child New Shared Care Plan

12. The following questions will ask about the child for whom the shared care plan was created. On what date was the shared care planning meeting held? *(Please type the date in the space below using mm/dd/yyyy format.)*

___ / ___ / ___

13. Which of following are members of the child's health team? *(Please check one response for each.)*

*If
yes
→*

14. If yes, how did the team member participate in the shared care planning meeting? *(Please check one response for each.)*

	Yes	No	NA *		In Person	By Phone	By Video	Written comment	Did not participate
a. Dental or Orthodontic Health	☐	☐	☐		☐	☐	☐	☐	☐
b. DHS Child Welfare	☐	☐	☐		☐	☐	☐	☐	☐
c. DHS Developmental Disabilities (DD) Services	☐	☐	☐		☐	☐	☐	☐	☐
d. Early Intervention/Early Childhood Special Education (EI/ECSE)	☐	☐	☐		☐	☐	☐	☐	☐
e. Preschool (e.g., Head Start, Pre-K Programs, private, etc.) or School (e.g., classroom or special education teacher, school nurse, etc.)	☐	☐	☐		☐	☐	☐	☐	☐
f. Child care provider	☐	☐	☐		☐	☐	☐	☐	☐
g. Family member(s)	☐	☐	☐		☐	☐	☐	☐	☐
h. Insurer (public, private, or both)	☐	☐	☐		☐	☐	☐	☐	☐
i. Mental/Behavioral Health	☐	☐	☐		☐	☐	☐	☐	☐
j. Primary medical care (e.g., MD, RN, care coordinator, etc.)	☐	☐	☐		☐	☐	☐	☐	☐
k. Specialty medical care	☐	☐	☐		☐	☐	☐	☐	☐
l. Occupational, physical, or speech therapist	☐	☐	☐		☐	☐	☐	☐	☐
m. Relief Nursery	☐	☐	☐		☐	☐	☐	☐	☐
n. WIC	☐	☐	☐		☐	☐	☐	☐	☐
o. Other, <i>please specify:</i>	☐	☐	☐		☐	☐	☐	☐	☐

*Sheryl, please spell out "Not Applicable" in REDCap.

15. Is this child currently part of your LHD's CaCoon caseload?

- ☐ Yes
☐ No

16. Did someone outside of your LHD refer this child to you to receive shared care planning?

- ☐ Yes → Continue to Question 17
☐ No → Skip to Question 18

17. Who referred this child to you to receive shared care planning? (Please check all that apply)

Source	Yes	No
a. Child care provider	☐	☐
b. Preschool teacher (e.g., Head Start, Pre-K Programs, private, etc.)	☐	☐
c. DD Services staff	☐	☐
d. Early Intervention/Early Childhood Special Education (EI/ECSE) staff	☐	☐
e. Insurer (public or private)	☐	☐
f. Mental/behavioral health provider	☐	☐
g. School staff (e.g., classroom or special education teacher, school nurse, etc.)	☐	☐
h. Primary care provider	☐	☐
i. Hospital or tertiary care center staff	☐	☐
j. Other, <i>please specify</i> : _____	☐	☐

18. What were the reasons that your staff decided to create a shared care plan for this child? (Please check all that apply.)

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- ☐ The child is a CaCoon client.
- ☐ The child's medical conditions are complex.
- ☐ The child or family has considerable unmet basic needs or environmental risks.
- ☐ The child poses a particular worry or concern to the provider.
- ☐ The child's family experiences difficulty getting the services or supports that they need.
- ☐ The child's family has trouble making, keeping, or getting to appointments.
- ☐ The child's family struggles to follow through with agreed upon actions or plans.
- ☐ The child has an undiagnosed condition.
- ☐ The family indicated that they need more help or support.
- ☐ Other, *please specify:* _____

19. Did the family receive a copy of the shared care plan?

- ☐ Yes
- ☐ No

20. To the best of your recollection, has this child received care from an emergency department in the past 12 months? (Please check one response.)

- ☐ Yes
- ☐ No

- ☐ I don't know

21. Is the child currently living with a foster care family? (Please check one response.)

- ☐ Yes
- ☐ No

- ☐ I don't know

22. How many years old is the child? (If the child is less than 1 year old, enter "0.")

_____ years

23. To the best of your knowledge, how does the child's family identify the child's race or ethnicity? (Please check all that apply.)

- ☐ American Indian / Alaska Native (This includes American Indians; Alaska Natives; Canadian Inuit, Metis, or First Nation; Indigenous Mexican, Central American, or South American.)
- ☐ African American / Black (This includes African American; African [Black]; Caribbean [Black]; Other Black.)

- ☐ Asian (*This includes Asian Indian; Chinese; Filipino/a; Hmong; Japanese; Korean; Laotian; South Asian; Vietnamese; Other Asian.*)
- ☐ Caucasian / White (*This includes Eastern European; Slavic; Western European; Other White.*)
- ☐ Hispanic or Latino/a (*This includes Hispanic or Latino Central American; Hispanic or Latino Mexican; Hispanic or Latino South American; Other Hispanic or Latino.*)
- ☐ Native Hawaiian / Pacific Islander (*This includes Guamanian or Chamorro; Micronesian; Native Hawaiian; Samoan; Tongan; Other Pacific Islander.*)
- ☐ Other (*Please specify: _____*)
-- -- --
- ☐ I don't know

24. What is the gender identity of the child? (*Please check one response.*)

- ☐ Female
- ☐ Male
- ☐ Other (e.g., gender nonconforming, transgender), *please specify:* _____
-- -- --
- ☐ I don't know

25. What is the primary language of the child's family? (*Please check one response.*)

- ☐ Cantonese
- ☐ English
- ☐ Mandarin
- ☐ Russian
- ☐ Spanish
- ☐ Vietnamese
- ☐ Other, *please specify:* _____

26. In your experience, how well does the child's family comprehend materials written in English? (*Please check one response.*)

- ☐ Very well
- ☐ Well
- ☐ Not well
- ☐ Not at all well
- -- --
- ☐ I can't tell

Young Adult New Shared Care Plan

27. Are you reporting the initiation of a new shared care plan or the re-evaluation of an existing shared care plan? *(Please check one response.)*

- ☐ New → *Continue to Question 28*
☐ Re-evaluation → *Skip to Question 62*

28. The following questions will ask about the young adult for whom the shared care plan was created. On what date was the shared care planning meeting held? *(Please type the date in the space below using mm/dd/yyyy format.)*

____ / ____ / ____

29. Which of following are members of the young adult's health team? *(Please check one response for each.)*

*If
yes
→*

30.. If yes, how did the team member participate in the shared care planning meeting? *(Please check one response for each.)*

	Yes	No	NA	In Person	By Phone	By Video	Written comment	Did not participate
a. The young adult (for whom the shared care plan is being created)	☐	☐	☐	☐	☐	☐	☐	☐
b. Dental or Orthodontic Health	☐	☐	☐	☐	☐	☐	☐	☐
c. DHS Child Welfare	☐	☐	☐	☐	☐	☐	☐	☐
d. DHS Developmental Disabilities (DD) Services	☐	☐	☐	☐	☐	☐	☐	☐
e. School (e.g., classroom or special education teacher, school nurse)	☐	☐	☐	☐	☐	☐	☐	☐
f. Family member(s)	☐	☐	☐	☐	☐	☐	☐	☐
g. Insurer (public, private, or both)	☐	☐	☐	☐	☐	☐	☐	☐
h. Mental/Behavioral Health	☐	☐	☐	☐	☐	☐	☐	☐
i. Primary medical care (e.g., MD, RN, care coordinator)	☐	☐	☐	☐	☐	☐	☐	☐
j. Specialty medical care	☐	☐	☐	☐	☐	☐	☐	☐
k. Occupational, physical, or speech therapist	☐	☐	☐	☐	☐	☐	☐	☐
l. Other, <i>please specify:</i>	☐	☐	☐	☐	☐	☐	☐	☐

31. Is this young adult currently part of your LHD's CaCoon caseload?

- ☐ Yes
☐ No

32. Did someone outside of your LHD refer this young adult to you to receive shared care planning?

- ☐ Yes → Continue to Question 33
☐ No → Skip to Question 34

33. Who referred this young adult to you to receive shared care planning? (Please check one for each.)

Source	Yes	No
a. DD Services staff	☐	☐
b. Insurer (public or private)	☐	☐
c. Mental/behavioral health provider	☐	☐
d. School staff (e.g., classroom or special education teacher, school nurse, etc.)	☐	☐
e. Primary or specialty provider	☐	☐
f. Hospital or tertiary care center staff	☐	☐
g. Other, please specify: _____	☐	☐

34. What were the reasons that your staff decided to create a shared care plan for this young adult? (Please check all that apply.)

- ☐ The young adult is a CaCoon client.
☐ The young adult's medical conditions are complex.
☐ The young adult or family has considerable unmet basic needs or environmental risks.
☐ The young adult poses a particular worry or concern to the provider.
☐ The young adult or their family experiences difficulty getting the services or supports that they need.
☐ The young adult's family has trouble making, keeping, or getting to appointments.
☐ The young adult's family struggles to follow through with agreed upon actions or plans.
☐ The young adult has an undiagnosed condition.
☐ The young adult is in need of support to transition from a pediatric to an adult model of health care (e.g., young adult cannot yet explain their medical needs to others; recognize symptoms of their conditions, including those indicating a medical emergency; identify an adult care provider; make their own medical appointments or arrange transportation to appointments).
☐ The family requires support to understand changes that will occur when their child transitions from a pediatric to an adult model of health care (e.g., legal changes, such as changes in decision-making,

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privacy, and consent when their young adult turns 18; changes in insurance and access to care when their young adult turns 18).

- ☐ The family indicated that they need more help or support.
- ☐ Other, please specify: _____

35. Do one or more of the young adult's goals address transitioning to an adult model of health care?

(Please check one response.)

- ☐ Yes → Continue to Question 36
- ☐ No → SKIP to Question 37

36. What is the transition goal(s)? *(Please write the goal(s) in the space that follows.)*

a.
b.
c.
d.

37. Did the young adult and family receive a copy of the shared care plan?

- ☐ Yes
- ☐ No

38. To the best of your recollection, has this young adult received care from an emergency department in the past 12 months? *(Please check one response.)*

- ☐ Yes
- ☐ No
-
- ☐ I don't know

39. How many years old is the young adult? *(Please type a number in the space below.)*

_____ years

40. To the best of your knowledge, how does the young adult identify their race or ethnicity? *(Please check all that apply.)*

- ☐ American Indian / Alaska Native *(This includes American Indians; Alaska Natives; Canadian Inuit, Metis, or First Nation; Indigenous Mexican, Central American, or South American.)*
- ☐ African American / Black *(This includes African American; African [Black]; Caribbean [Black]; Other Black.)*
- ☐ Asian *(This includes Asian Indian; Chinese; Filipino/a; Hmong; Japanese; Korean; Laotian; South Asian; Vietnamese; Other Asian.)*

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- ☐ Caucasian / White *(This includes Eastern European; Slavic; Western European; Other White.)*
- ☐ Hispanic or Latino/a *(This includes Hispanic or Latino Central American; Hispanic or Latino Mexican; Hispanic or Latino South American; Other Hispanic or Latino.)*
- ☐ Native Hawaiian / Pacific Islander *(This includes Guamanian or Chamorro; Micronesian; Native Hawaiian; Samoan; Tongan; Other Pacific Islander.)*
- ☐ Other *(Please specify: _____)*

- ☐ I don't know

41. What is the gender identity of the young adult? *(Please check one response.)*

- ☐ Female
- ☐ Male
- ☐ Other (e.g., gender nonconforming, transgender), *please specify:* _____

- ☐ I don't know

42. What is the primary language of the young adult? *(Please check one response.)*

- ☐ Cantonese
- ☐ English
- ☐ Mandarin
- ☐ Russian
- ☐ Spanish
- ☐ Vietnamese
- ☐ Other, *please specify:* _____

43. In your experience, how well does the young adult comprehend materials written in English? *(Please check one response.)*

- ☐ Very well
- ☐ Well
- ☐ Not well
- ☐ Not at all well
-
- ☐ I can't tell

Child Re-evaluation Shared Care Plan

44. The following questions will ask about the child for whom the shared care plan was re-evaluated. On what date was the shared care plan re-evaluated? (Please type the date in the space below using mm/dd/yyyy format.)

___ / ___ / ___

45. On what date was this child's shared care plan initially created? (Please type the date in the space below using mm/dd/yyyy format.)

___ / ___ / ___

46. Which of following are members of the child's health team? (Please check one response for each.)

If
yes
→

47. If yes, how did the team member participate in the shared care plan meeting? (Please check one response for each.)

	Yes	No	NA		In Person	By Phone	By Video	Written comment	Did not participate
a. Dental or Orthodontic Health	☐	☐	☐		☐	☐	☐	☐	☐
b. DHS Child Welfare	☐	☐	☐		☐	☐	☐	☐	☐
c. DHS Developmental Disabilities (DD) Services	☐	☐	☐		☐	☐	☐	☐	☐
d. Early Intervention/Early Childhood Special Education (EI/ECSE)	☐	☐	☐		☐	☐	☐	☐	☐
e. Preschool (e.g., Head Start, Pre-K Programs, private, etc.) or School (e.g., classroom or special education teacher, school nurse, etc.)	☐	☐	☐		☐	☐	☐	☐	☐
f. Child care provider	☐	☐	☐		☐	☐	☐	☐	☐
g. Family member(s)	☐	☐	☐		☐	☐	☐	☐	☐
h. Insurer (public, private, or both)	☐	☐	☐		☐	☐	☐	☐	☐
i. Mental/Behavioral Health	☐	☐	☐		☐	☐	☐	☐	☐
j. Primary medical care (e.g., MD, RN, care coordinator, etc.)	☐	☐	☐		☐	☐	☐	☐	☐
k. Specialty medical care	☐	☐	☐		☐	☐	☐	☐	☐
l. Occupational, physical, or speech therapist	☐	☐	☐		☐	☐	☐	☐	☐
m. Relief Nursery	☐	☐	☐		☐	☐	☐	☐	☐
n. WIC	☐	☐	☐		☐	☐	☐	☐	☐
o. Other, please specify:	☐	☐	☐		☐	☐	☐	☐	☐

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48. Where does your local public health department store this child's shared care plan? *(Please enter your response in the space below.)*

49. How many goals did the initial shared care plan include? *(Please enter a number in the space below.)*

_____ goals

50. Of those goals, how many were completed by the time of the re-evaluation? *(Please enter a number in the space below.)*

_____ completed goals

51. When the child health team members complete their assigned actions, how did they let other team members, including the family, know of their completion? *(Please enter your response in the space below.)*

52. Did the child health team create new goals when this shared care plan was re-evaluated? *(Please check one response.)*

- ☐ Yes → Continue to Question 53
☐ No → Skip to Question 54

53. How many new goals were created? *(Please enter a number in the space below.)*

_____ new goals

54. Did the family receive a copy of the re-evaluated shared care plan?

- ☐ Yes
☐ No

55. To the best of your recollection, has this child received care from an emergency department in the past 12 months? *(Please check one response.)*

- ☐ Yes
☐ No
☐ I don't know

56. Is the child currently living with a foster care family? *(Please check one response.)*

- ☐ Yes
- ☐ No
- ☐ I don't know

57. How many years old is the child? *(If the child is less than 1 year old, enter "0.")*

_____ years

58. To the best of your knowledge, how does the child's family identify the child's race or ethnicity? *(Please check all that apply.)*

- ☐ American Indian / Alaska Native *(This includes American Indians; Alaska Natives; Canadian Inuit, Metis, or First Nation; Indigenous Mexican, Central American, or South American.)*
- ☐ African American / Black *(This includes African American; African [Black]; Caribbean [Black]; Other Black.)*
- ☐ Asian *(This includes Asian Indian; Chinese; Filipino/a; Hmong; Japanese; Korean; Laotian; South Asian; Vietnamese; Other Asian.)*
- ☐ Caucasian / White *(This includes Eastern European; Slavic; Western European; Other White.)*
- ☐ Hispanic or Latino/a *(This includes Hispanic or Latino Central American; Hispanic or Latino Mexican; Hispanic or Latino South American; Other Hispanic or Latino.)*
- ☐ Native Hawaiian / Pacific Islander *(This includes Guamanian or Chamorro; Micronesian; Native Hawaiian; Samoan; Tongan; Other Pacific Islander.)*
- ☐ Other *(Please specify: _____)*
-- -- --
- ☐ I don't know

59. What is the gender identity of the child? *(Please check one response.)*

- ☐ Female
- ☐ Male
- ☐ Other (e.g., gender nonconforming, transgender), *please specify:* _____
-- -- --
- ☐ I don't know

60. What is the primary language of the child's family? *(Please check one response.)*

- ☐ Cantonese
- ☐ English
- ☐ Mandarin
- ☐ Russian
- ☐ Spanish
- ☐ Vietnamese
- ☐ Other, *please specify:* _____

61. In your experience, how well does the child's family comprehend materials written in English? *(Please check one response.)*

- ☐ Very well
- ☐ Well
- ☐ Not well
- ☐ Not at all well
-
- ☐ I can't tell

Young Adult Re-evaluation Shared Care Plan

62. The following questions will ask about the young adult for whom the shared care plan was re-evaluated. On what date was the shared care plan re-evaluated? *(Please type the date in the space below using mm/dd/yyyy format.)*

___ / ___ / ___

63. On what date was this young adult's shared care plan initially created? *(Please type the date in the space below using mm/dd/yyyy format.)*

___ / ___ / ___

64. Which of following are members of the young adult's health team? *(Please check one response for each.)*

If
yes
→

65. If yes, how did the team member participate in the shared care planning meeting? *(Please check one response for each.)*

	Yes	No	NA		In Person	By Phone	By Video	Written comment	Did not participate
a. The young adult (for whom the shared care plan is being created)	☐	☐	☐		☐	☐	☐	☐	☐
b. Dental or Orthodontic Health	☐	☐	☐		☐	☐	☐	☐	☐
c. DHS Child Welfare	☐	☐	☐		☐	☐	☐	☐	☐
d. DHS Developmental Disabilities (DD) Services	☐	☐	☐		☐	☐	☐	☐	☐
e. School (e.g., classroom or special education teacher, school nurse)	☐	☐	☐		☐	☐	☐	☐	☐
f. Family member(s)	☐	☐	☐		☐	☐	☐	☐	☐
g. Insurer (public, private, or both)	☐	☐	☐		☐	☐	☐	☐	☐
h. Mental/Behavioral Health	☐	☐	☐		☐	☐	☐	☐	☐
i. Primary medical care (e.g., MD, RN, care coordinator)	☐	☐	☐		☐	☐	☐	☐	☐
j. Specialty medical care	☐	☐	☐		☐	☐	☐	☐	☐
k. Occupational, physical, or speech therapist	☐	☐	☐		☐	☐	☐	☐	☐
l. Other, please specify:	☐	☐	☐		☐	☐	☐	☐	☐

66. Where does your local public health department store this young adult's shared care plan? *(Please enter your response in the space below.)*

67. How many goals did the initial shared care plan include? *(Please enter a number in the space below.)*

_____ goals

68. Of those goals, how many were completed by the time of the re-evaluation? *(Please enter a number in the space below.)*

_____ completed goals

69. When the child health team members completed their assigned actions, how did they let other team members, including the family, know of their completion? *(Please enter your response in the space below.)*

70. Did the child health team create new goals when this shared care plan was re-evaluated? *(Please check one response.)*

☐ Yes → Continue to Question 71

☐ No → Skip to Question 72

71. How many new goals were created? *(Please enter a number in the space below.)*

_____ new goals

72. Does one or more of the shared care plan goals address transitioning to an adult model of health care? *(Please check one response.)*

☐ Yes → Continue to Question 73

☐ No → SKIP to Question 75

73. What is the transition goal(s)? *(Please write the goal(s) in the space that follows.)*

a.

b.

c.

d.

74. Has the transition goal(s) been completed? *(Please check one response.)*

- ☐ Yes, all of the transition goals have been completed.
- ☐ Yes, some of the transition goals have been completed.
- ☐ No, none of the transition goals have been completed.

75. Did the young adult and family receive a copy of the re-evaluated shared care plan?

- ☐ Yes
- ☐ No

76. To the best of your recollection, has this young adult received care from an emergency department in the past 12 months? *(Please check one response.)*

- ☐ Yes
- ☐ No
-
- ☐ I don't know

77. How many years old is the young adult? *(Please type a number in the space below.)*

_____ years

78. To the best of your knowledge, how does the young adult identify their race or ethnicity? *(Please check all that apply.)*

- ☐ American Indian / Alaska Native *(This includes American Indians; Alaska Natives; Canadian Inuit, Metis, or First Nation; Indigenous Mexican, Central American, or South American.)*
- ☐ African American / Black *(This includes African American; African [Black]; Caribbean [Black]; Other Black.)*
- ☐ Asian *(This includes Asian Indian; Chinese; Filipino/a; Hmong; Japanese; Korean; Laotian; South Asian; Vietnamese; Other Asian.)*
- ☐ Caucasian / White *(This includes Eastern European; Slavic; Western European; Other White.)*
- ☐ Hispanic or Latino/a *(This includes Hispanic or Latino Central American; Hispanic or Latino Mexican; Hispanic or Latino South American; Other Hispanic or Latino.)*
- ☐ Native Hawaiian / Pacific Islander *(This includes Guamanian or Chamorro; Micronesian; Native Hawaiian; Samoan; Tongan; Other Pacific Islander.)*

OCCYSHN - Local Health Department (LHD)
Revised Shared Care Plan Information Form – All Forms 10/29/2018

☐ Other (Please specify: _____)

☐ I don't know

79. What is the gender identity of the young adult? (Please check one response.)

☐ Female

☐ Male

☐ Other (e.g., gender nonconforming, transgender), please specify: _____

☐ I don't know

80. What is the primary language of the young adult? (Please check one response.)

☐ Cantonese

☐ English

☐ Mandarin

☐ Russian

☐ Spanish

☐ Vietnamese

☐ Other, please specify: _____

81. In your experience, how well does the young adult comprehend materials written in English? (Please check one response.)

☐ Very well

☐ Well

☐ Not well

☐ Not at all well

☐ I can't tell



**Experiences Working with Your Child's
Health and Other Care Professionals**

Parent/Guardian Study Interest Form

I am being asked if a study team member from the Oregon Center for Children and Youth with Special Health Needs may contact me with a survey in two to four months. The survey asks questions about working with providers who care for my child. I understand that I may refuse to participate in the survey. If I decline to have the study team member contact me, this will not affect the services my child or I receive from the county public health department.

Are you interested in participating in this survey? If yes, please complete the following questions.

a. What is your name? _____

b. How would you like to fill out the survey?

☐ Online (*We will email you the survey*)

☐ On paper (*We will mail you the survey with a pre-paid return envelope included*)

c. If you prefer to fill out an online survey, what is the best email address to use to send you the survey?

d. If you prefer to fill out a paper survey, what is the best mailing address to use to mail you the survey?

Street address: _____

City: _____

State: _____

Zipcode: _____

Date: _____



**Experiencias colaborando con los
proveedores de atención y otros profesionales de salud de su hijo**

Formulario de interés sobre un estudio para el padre/tutor

Se me solicita si un miembro del equipo del estudio del Centro de Oregon para Niños y Jóvenes con Necesidades Especiales de Salud me puede contactar para realizar una encuesta dentro de dos a cuatro meses. La encuesta incluye preguntas sobre mi colaboración con los proveedores que atienden a mi hijo. Entiendo que puedo negarme a participar en esta encuesta. Si me niego a que el miembro del equipo del estudio me contacte, esto no afectará los servicios que mi hijo o yo recibimos del departamento de salud pública del condado.

¿Está interesado(a) en participar en esta encuesta? Si es así, complete las siguientes preguntas.

a. ¿Cuál es su nombre? _____

b. ¿Cómo le gustaría completar la encuesta?

- ☐ En línea (*Le enviaremos la encuesta por correo electrónico*)
☐ En papel (*Le enviaremos la encuesta por correo con un sobre de retorno prepagado*)

c. Si prefiere completar la encuesta en línea, ¿cuál es la mejor dirección de correo electrónico que debemos usar para enviarle la encuesta?

d. Si prefiere completar la encuesta en papel ¿cuál es la mejor dirección de correo que debemos usar para enviarle la encuesta?

Dirección: _____

Ciudad: _____

Estado: _____

Código postal: _____

Fecha: _____

**SURVEY OF FAMILY EXPERIENCES
WORKING WITH THEIR CHILD'S
CARE PROVIDERS**

An effort to understand families' experiences working with
multiple care providers for their child.

For families with a child with special health care needs.

Oregon Center for Children and Youth with Special Health Needs
Institute on Development & Disability
Oregon Health & Science University
Portland, Oregon

Experiences Working with Your Child's Health and Other Care Professionals Family Survey

The Oregon Center for Children and Youth with Special Health Needs (OCCYSHN) promotes optimal health, development, and well-being of Oregon's children and youth with special health needs. OCCYSHN is trying to understand how child health teams work together to help children and youth with special health care needs get the care that they need. Members of child health teams include families, local health department staff, doctors, nurses, educators, therapists, specialty medical providers, and others. Children and youth with special health care needs either have chronic health conditions, or they are at risk for having them. Those conditions can be physical, developmental, behavioral, or emotional. These children need health care and other services more than other children. Within the last two to four months you and your child have visited with a child health team.

We sent this survey to you because you told the child health team you would be willing to complete it. The answers you give helps OCCYSHN learn what it is like for you to work with several different care providers (such as doctors, nurses, educators, specialists, therapists, and others) to care for your child. The answers that all families who fill out this survey will be used to improve care planning for children and families who work with many different providers.

Your input is confidential! OCCYSHN staff are the only people who will see your answers. When OCCYSHN receives completed surveys, our staff will combine the responses from all of the families into a summary.

Your input is important! We need to hear from as many families as possible to understand what it is like for you to work with several different care providers. We hope that you will spend about 10 minutes completing our survey but if you do not want to, you do not have to. You do not have to answer every question. You also may choose to quit the survey at any time.

Risks: Although we have made every effort to protect your identity, there is a minimal risk of loss of confidentiality.

Benefits: Families who complete the survey will receive a \$25 prepaid vendor card. Your answers may help OCCYSHN learn how to benefit other children and families in the future.

Costs: It will not cost you anything to complete the survey.

Participation: This survey is being overseen by an Institutional Review Board ("IRB"). You may talk to the IRB at 503-494-7887 or irb@ohsu.edu if:

- Your questions, concerns, or complaints are not being answered by the research team.
- You want to talk to someone besides the research team.
- You have questions about your rights as a research subject.
- You want to get more information or provide input about this research.

You may also submit a report to the OHSU Integrity Hotline online at <https://secure.ethicspoint.com/domain/media/en/gui/18915/index.html> or by calling toll-free 877-733-8313 (anonymous and available 24 hours a day, 7 days a week).

If you have any questions, concerns, or complaints regarding this survey now or in the future, you can call or email us.

Alison J. Martin, Ph.D.
Principal Investigator
Assessment & Evaluation Coordinator
503-494-5435
martial@ohsu.edu

Sheryl Gallarde, MSc
Project Coordinator
Assessment & Evaluation Research Associate
503-494-2723
gallarde@ohsu.edu

OHSU IRB No. STUDY00016550

Start Here

1. **Does your child currently need or use medicine prescribed by a doctor, other than vitamins?** *(Please check one response.)*
☐ Yes
☐ No
2. **Does your child need or use more medical care, mental health, or educational services than is usual for most children of the same age?** *(Please check one response.)*
☐ Yes
☐ No
3. **Is your child limited or prevented in any way in his or her ability to do the things that most children of the same age can do?** *(Please check one response.)*
☐ Yes
☐ No

4. **Does your child need or get special therapy, such as physical, occupational, or speech therapy?** *(Please check one response.)*
☐ Yes
☐ No
5. **Does your child have any kind of emotional, developmental, or behavioral problem for which he or she needs treatment or counseling?** *(Please check one response.)*
☐ Yes
☐ No
6. **Have your child's needs lasted or are they expected to last 12 months or longer?** *(Please check one response.)*
☐ Yes
☐ No

7. **In the last 12 months, about how many times has your child needed or used the following types of care or service?**

	Never	One time	Two or more times
a. A medical doctor, physician assistant, or nurse	☐	☐	☐
b. Occupational, physical, or speech therapy	☐	☐	☐
c. Home health care	☐	☐	☐
d. Transportation services	☐	☐	☐
e. Specialists (doctors like surgeons, heart doctors, allergy doctors, mental health doctors, or others who specialize in one area of health care)	☐	☐	☐
f. Early intervention services	☐	☐	☐
g. Special education services	☐	☐	☐
h. Respite care services	☐	☐	☐
i. Other, <i>please specify:</i> _____	☐	☐	☐

8. **Have you or other family members stopped working because of your child's health?** *(Please check one response.)*
- ☐ Yes
☐ No
9. **Have you or other family members cut down on the hours you work because of your child's health?** *(Please check one response.)*
- ☐ Yes
☐ No
10. **In the last 4 weeks, about how many hours per week did you spend managing the care your child was getting from different doctors or care providers, including making sure that information was shared between all of these providers?** *(Please check one response.)*
- ☐ Less than 1 hour each week
☐ 1 to 10 hours each week
☐ 11 to 20 hours each week
☐ 21 to 39 hours each week
☐ More than 40 hours each week
11. **Is that more or less time than you usually spend managing your child's care?** *(Please check one response.)*
- ☐ More time than I usually spend managing my child's care
☐ About the same amount of time I usually spend managing my child's care
☐ Less time than I usually spend managing my child's care
12. **How stressful is it for you to manage your child's care?** *(Please check one response.)*
- ☐ Very stressful
☐ Somewhat stressful
☐ A little stressful
☐ Not at all stressful
13. **A shared care plan is a written document that contains information about your child's active health problems, medicines he or she is taking, special considerations that all people caring for your child should**

know, goals for your child's health, growth and development, and steps to take to reach those goals. It is different than an Individualized Education Program (IEP).

Has anyone explained to you the value of your child having a shared care plan?

(Please check one response.)

- ☐ Yes
☐ No

14. **Does your child have a shared care plan?**

(Please check one response.)

- ☐ Yes
☐ No → *SKIP to #22*

15. **Who took part in creating your child's shared care plan?**

(Please write your response in the space below.)

16. **Did you take part in creating your child's shared care plan?** *(Please check one response.)*

- ☐ Yes
☐ No → *SKIP to Question 18*

17. **Did you feel your input was respected by the people who helped you create the shared care plan?** *(Please check one response.)*

- ☐ Yes definitely
☐ Yes somewhat
☐ No

18. **Do you have a copy of your child's shared care plan?** *(Please check one response.)*

- ☐ Yes
☐ No
☐ I don't know

19. Does the shared care plan include...? (Please check one for each.)

	Yes	No	I don't know
a. A brief medical summary	☐	☐	☐
b. Your child's strengths	☐	☐	☐
c. Your child's needs	☐	☐	☐
d. Goals that you or your child wanted	☐	☐	☐
e. Goals that your providers wanted	☐	☐	☐
f. Action steps	☐	☐	☐
g. Who is responsible for each step	☐	☐	☐
h. A timeline (date) for action or completion	☐	☐	☐

20. Does your child's shared care plan work well with your family's values and culture? (Please check one response.)

- ☐ Yes Definitely
☐ Yes Somewhat
☐ No

21. In the last 6 months, has anyone talked with you about the progress your child was making toward the goals written in his or her shared care plan? (Please check one response.)

- ☐ Yes
☐ No
☐ My child's shared care plan does not have written goals

22. How many years old is your child? (Please enter the number in the space below. If your child is less than 1 year old, enter "00.")

23. What is your child's gender identity? (Please check one response.)

- ☐ Female
☐ Male
☐ Other, please specify: _____
☐ Decline to answer

24. Is your child of Hispanic or Latino origin or descent? (Please check one response.)

- ☐ Yes
☐ No

25. What is your child's race? (Please check all that apply.)

- ☐ American Indian / Alaska Native
☐ African American / Black
☐ Asian
☐ Caucasian / White
☐ Native Hawaiian / Pacific Islander
☐ Multiracial
☐ Other race (Please specify.) _____

26. What is your relationship to the child you described in this survey? (Please check one response.)

- ☐ Parent
☐ Foster parent
☐ Grandparent
☐ Aunt or uncle
☐ Brother or sister
☐ Other legal guardian
☐ Other, please specify: _____

27. What is your age?

(Please check one response.)

- ☐ Under 18 years
- ☐ 18 to 24 years
- ☐ 25 to 34 years
- ☐ 35 to 44 years
- ☐ 45 to 54 years
- ☐ 55 to 64 years
- ☐ 65 to 74 years
- ☐ 75 years or older

28. Are you of Hispanic or Latino origin or descent? (Please check one response.)

- ☐ Yes
- ☐ No

29. What is your race?

(Please check all that apply.)

- ☐ American Indian / Alaska Native
- ☐ African American / Black
- ☐ Asian
- ☐ Caucasian / White
- ☐ Native Hawaiian / Pacific Islander
- ☐ Multiracial
- ☐ Other race (Please specify: _____)

30. What language do you most often speak at home? (Please check one response.)

- ☐ Cantonese
- ☐ English
- ☐ Mandarin
- ☐ Russian
- ☐ Spanish
- ☐ Vietnamese
- ☐ Other, please specify: _____

31. What is the highest grade or level of school that you have completed?

(Please check one response.)

- ☐ 8th grade or less
- ☐ Some high school, but did not graduate
- ☐ High school graduate or GED
- ☐ Some college or 2-year degree
- ☐ 4-year college graduate, or
- ☐ More than 4-year college degree

32. What county are you living in now?

(Please check one response.)

- ☐ Baker
- ☐ Benton
- ☐ Clackamas
- ☐ Clatsop
- ☐ Columbia
- ☐ Coos
- ☐ Crook
- ☐ Curry
- ☐ Deschutes
- ☐ Douglas
- ☐ Gilliam
- ☐ Grant
- ☐ Harney
- ☐ Hood River
- ☐ Jackson
- ☐ Jefferson
- ☐ Josephine
- ☐ Klamath
- ☐ Lake
- ☐ Lane
- ☐ Lincoln
- ☐ Linn
- ☐ Malheur
- ☐ Marion
- ☐ Morrow
- ☐ Multnomah
- ☐ Polk
- ☐ Sherman
- ☐ Tillamook
- ☐ Umatilla
- ☐ Union
- ☐ Wallowa
- ☐ Wasco
- ☐ Washington
- ☐ Wheeler
- ☐ Yamhill

Thank you for your feedback!

Please return your survey in the enclosed stamped envelope.

ENCUESTA SOBRE LAS
EXPERIENCIAS DE LA FAMILIA
COLABORANDO CON LOS
PROVEEDORES DE ATENCIÓN DE SU
HIJO

Un esfuerzo para comprender las experiencias de las familias
colaborando con múltiples proveedores de atención de su
hijo.

Para familias con un niño con necesidades especiales de
atención de salud.

Centro de Oregón para Niños y Jóvenes con Necesidades Especiales de Salud
(Oregon Center for Children and Youth with Special Health Needs, OCCYSHN)
Instituto de Desarrollo y Discapacidad (Institute on Development & Disability)
Universidad de Salud y Ciencia de Oregón (Oregon Health & Science University)
Portland, Oregón

Experiencias colaborando con los proveedores de atención y otros profesionales de salud de su hijo

Encuesta familiar

El Centro de Oregón para Niños y Jóvenes con Necesidades Especiales de Salud (Oregon Center for Children and Youth with Special Health Needs, OCCYSHN) promueve la salud, el desarrollo y el bienestar óptimos de niños y jóvenes con necesidades especiales de salud de Oregón. El OCCYSHN quiere comprender cómo los equipos de salud de los niños colaboran para ayudar a los niños y a los jóvenes con necesidades especiales de atención de salud para que reciban la atención que necesitan. Los miembros de los equipos de salud de los niños incluyen sus familias, el personal del departamento de salud pública del condado, los médicos, las enfermeras, los educadores, los terapeutas, los proveedores médicos especialistas y otros. Los niños y los jóvenes con necesidades especiales de atención de salud tienen afecciones de salud crónicas o corren riesgo de tenerlas. Estas afecciones pueden ser físicas, de desarrollo, de comportamiento o emocionales. Estos niños necesitan atención de salud y otros servicios más que otros niños. Dentro de los últimos dos a cuatro meses usted y su hijo se han reunido con un equipo de salud de niños.

Le enviamos esta encuesta porque usted le mencionó a su equipo de salud de niños que está dispuesto(a) a completarla. Sus respuestas ayudarán a que el OCCYSHN aprenda sobre su experiencia colaborando con varios proveedores de salud diferentes (como médicos, enfermeras, educadores, especialistas, terapeutas y otros) en el cuidado de su hijo. Las respuestas de todas las familias que completen esta encuesta se utilizarán para mejorar el planeamiento de la atención de niños y familias que colaboran con muchos proveedores diferentes.

¡Su contribución es confidencial! Las personas del personal del OCCYSHN serán las únicas que verán sus respuestas. Cuando el OCCYSHN reciba las encuestas completadas, nuestro personal combinará las respuestas de todas las familias en un resumen.

¡Su contribución es importante! Necesitamos escuchar del mayor número de familias posible para comprender cómo es su experiencia colaborando con varios proveedores de salud diferentes. Esperamos que completar la encuesta le tome unos 10 minutos, pero no la tiene que completar si no desea hacerlo. No tiene que responder todas las preguntas. También puede elegir dejar de responder la encuesta en cualquier momento.

Riesgos. A pesar de que hemos realizado todos los esfuerzos posibles para proteger su identidad, existe un riesgo mínimo de pérdida de la confidencialidad.

Beneficios. Enviaremos una tarjeta de regalo de \$25 para las familias que completen la encuesta. Sus respuestas podrían ayudar al OCCYSHN a comprender cómo beneficiar a otros niños y familias en el futuro.

Costos. No le costará nada completar la encuesta.

Participación. Esta encuesta está supervisada por una Junta de Revisión Institucional (Institutional Review Board, IRB). Puede comunicarse con la IRB al 503-494-7887 o irb@ohsu.edu si:

- El equipo de investigación no responde sus preguntas, preocupaciones o quejas.
- Desea hablar con alguien que no forme parte del equipo de investigación.
- Tiene preguntas sobre sus derechos como sujeto en una investigación.
- Desea obtener información adicional o aportar una contribución sobre este estudio.

También puede remitir un informe a la línea directa de Integridad de OHSU en línea al <https://secure.ethicspoint.com/domain/media/en/gui/18915/index.html> o llamando al número gratuito 877-733-8313 (de forma anónima y disponible las 24 horas, los 7 días a la semana).

Si tiene cualquier pregunta, preocupación o queja en relación con esta encuesta ahora o en el futuro, puede llamarnos o enviarnos un correo electrónico.

Alison J. Martin, Ph.D.
Investigadora Principal
Coordinadora de Evaluación y Valoración

503-494-5435
martial@ohsu.edu

Sheryl Gallarde, MSc
Coordinadora de Proyectos
Investigadora Asociada de Evaluación y Valoración

503-494-2723
gallarde@ohsu.edu

OHSU IRB ESTUDIO N.º 00016550

Comenzar aquí

1. **¿Necesita o usa actualmente su hijo medicamentos recetados por un médico, aparte de las vitaminas?** *(Marque una respuesta).*
☐ Sí
☐ No
2. **¿Necesita o usa su hijo más servicios de atención médica, salud mental o educacionales que lo habitual para niños de la misma edad?** *(Marque una respuesta).*
☐ Sí
☐ No
3. **¿Algo limita o impide a su hijo de cualquier manera en su habilidad de hacer las cosas que la mayoría de los niños de la misma edad pueden hacer?** *(Marque una respuesta).*
☐ Sí
☐ No

4. **¿Necesita o recibe su hijo terapias especiales como terapia física, ocupacional o del lenguaje?** *(Marque una respuesta).*
☐ Sí
☐ No
5. **¿Tiene su hijo algún tipo de problema emocional, de desarrollo o de comportamiento por el cual necesita un tratamiento o asesoramiento?** *(Marque una respuesta).*
☐ Sí
☐ No
6. **¿Las necesidades de su hijo han durado o se espera que duren 12 meses o más?** *(Marque una respuesta).*
☐ Sí
☐ No

7. **En los últimos 12 meses, ¿aproximadamente cuántas veces ha necesitado o usado su hijo los siguientes tipos de atención o servicio?**

	Nunca	Una vez	Dos o más veces
a. Un médico, asistente médico o enfermero	☐	☐	☐
b. Terapia ocupacional, física o del lenguaje	☐	☐	☐
c. Cuidado de salud en el hogar	☐	☐	☐
d. Servicios de transporte	☐	☐	☐
e. Especialistas (médicos como cirujanos, médicos del corazón, médicos de alergias, médicos de salud mental u otros que se especializan en un área de la atención de la salud)	☐	☐	☐
f. Servicios de intervención temprana	☐	☐	☐
g. Servicios de educación especial	☐	☐	☐
h. Servicios de respiro familiar	☐	☐	☐
i. Otro, <i>especifique:</i> _____	☐	☐	☐

8. ¿Ha tenido usted o algún otro miembro de la familia que dejar de trabajar debido a la salud de su hijo? *(Marque una respuesta).*

- ☐ Sí
☐ No

9. ¿Ha tenido usted o algún otro miembro de la familia que reducir el número de horas que trabajan por la salud de su hijo?

(Marque una respuesta).

- ☐ Sí
☐ No

10. En las últimas 4 semanas, ¿aproximadamente cuántas horas por semana pasó administrando la atención que su hijo recibía de diferentes médicos o proveedores de atención, incluido el asegurarse que la información se compartiera entre todos estos proveedores? *(Marque una respuesta).*

- ☐ Menos de 1 hora cada semana
☐ 1 a 10 horas cada semana
☐ 11 a 20 horas cada semana
☐ 21 a 39 horas cada semana
☐ Más de 40 horas cada semana

11. ¿Es eso más o menos tiempo de lo que habitualmente pasa administrando la atención de su hijo? *(Marque una respuesta).*

- ☐ Más tiempo de lo que habitualmente paso administrando la atención de mi hijo
☐ Alrededor de la misma cantidad de tiempo de lo que habitualmente paso administrando la atención de mi hijo
☐ Menos tiempo de lo que habitualmente paso administrando la atención de mi hijo

12. ¿Cuánto estrés le causa dirigir la atención de su hijo? *(Marque una respuesta).*

- ☐ Mucho estrés
☐ Algo de estrés
☐ Un poco de estrés
☐ Nada de estrés

13. Un plan de atención compartido es un documento escrito que contiene información acerca de los problemas de salud en progreso de su hijo, los medicamentos que él o ella está tomando, consideraciones especiales que todas las personas que cuidan a su hijo deben saber, las metas para la salud, el crecimiento y el desarrollo de su hijo y los pasos para alcanzar esas metas. Es diferente a un Programa de Educación Individualizado (Individualized Education Program, IEP).

¿Alguien le ha explicado el valor de que su hijo tenga un plan de atención compartido? *(Marque una respuesta).*

- ☐ Sí
☐ No

14. ¿Tiene su hijo un plan de atención compartido?

(Marque una respuesta).

- ☐ Sí
☐ No → PASE a la pregunta 22

15. ¿Quién participó en la creación del plan de atención compartido de su hijo?

(Escriba su respuesta en el espacio provisto a continuación).

16. ¿Participó en la creación del plan de atención compartido de su hijo? *(Marque una respuesta).*

- ☐ Sí
☐ No → PASE a la pregunta 18

17. ¿Consideró que las personas que lo ayudaron a crear el plan de atención compartieron su contribución?

(Marque una respuesta).

- ☐ Sí definitivamente
- ☐ Sí en cierto modo
- ☐ No

18. ¿Tiene una copia del plan de atención compartido de su hijo? (Marque una respuesta).

- ☐ Sí
- ☐ No
- ☐ No lo sé

19. ¿El plan de atención compartido incluye...? (Marque una para cada uno).

	Sí	No	No lo sé
a. Un resumen médico breve	☐	☐	☐
b. Las fortalezas de su hijo	☐	☐	☐
c. Las necesidades de su hijo	☐	☐	☐
d. Las metas que usted o su hijo deseaban	☐	☐	☐
e. Las metas que los proveedores deseaban	☐	☐	☐
f. Los pasos de acción	☐	☐	☐
g. Quién es responsable de cada paso	☐	☐	☐
h. Un cronograma (fecha) para la acción o su término	☐	☐	☐

20. ¿El plan de atención compartido de su hijo se adapta bien a los valores y la cultura de su familia?

(Marque una respuesta).

- ☐ Sí definitivamente
- ☐ Sí en cierto modo
- ☐ No

23. ¿Cuál es la identidad de género de su hijo? (Marque una respuesta).

- ☐ Femenino
- ☐ Masculino
- ☐ Otro, especifique: _____
- ☐ No deseo responder

21. En los últimos 6 meses, ¿ha hablado alguien con usted sobre el progreso que está haciendo su hijo con respecto a las metas escritas en su plan de atención compartido? (Marque una respuesta).

- ☐ Sí
- ☐ No
- ☐ El plan de atención compartido de mi hijo no tiene metas escritas

24. ¿Es su hijo de origen o ascendencia hispana o latina? (Marque una respuesta).

- ☐ Sí
- ☐ No

22. ¿Cuántos años tiene su hijo?

(Ingrese el número en el espacio provisto a continuación. Si su hijo tiene menos de 1 año de edad, ingrese "00").

25. ¿Cuál es la raza de su hijo?

(Marque todas las que correspondan).

- ☐ Nativo americano/Nativo de Alaska
- ☐ Afroamericano/Negro
- ☐ Asiático
- ☐ Caucásico/Blanco
- ☐ Nativo Hawaiano/Isleño del Pacífico
- ☐ Multirracial
- ☐ Otra raza (Especifique).

26. ¿Cuál es su relación de parentesco con el niño que describe en esta encuesta?

(Marque una respuesta).

- ☐ Padre/Madre
- ☐ Padre sustituto/Madre sustituta
- ☐ Abuelo(a)
- ☐ Tío(a)
- ☐ Hermano(a)
- ☐ Otro tutor legal
- ☐ Otro, especifique: _____

27. ¿Cuál es su edad?

(Marque una respuesta).

- ☐ Menor de 18 años
- ☐ 18 a 24 años
- ☐ 25 a 34 años
- ☐ 35 a 44 años
- ☐ 45 a 54 años
- ☐ 55 a 64 años
- ☐ 65 a 74 años
- ☐ 75 años o más

28. ¿Es de origen o ascendencia hispana o latina? (Marque una respuesta).

- ☐ Sí
- ☐ No

29. ¿Cuál es su raza?

(Marque todas las que correspondan).

- ☐ Nativo americano/Nativo de Alaska
- ☐ Afroamericano/Negro
- ☐ Asiático
- ☐ Caucásico/Blanco
- ☐ Nativo Hawaiano/Isleño del Pacífico
- ☐ Multirracial
- ☐ Otra raza (Especifique: _____)

30. ¿Qué idioma habla más a menudo en el hogar? (Marque una respuesta).

- ☐ Cantonés
- ☐ Inglés
- ☐ Mandarín
- ☐ Ruso
- ☐ Español
- ☐ Vietnamita
- ☐ Otro, especifique: _____

31. ¿Cuál es el grado o nivel más alto de educación que ha completado?

(Marque una respuesta).

- ☐ 8vo grado o menos
- ☐ Algo de escuela secundaria, pero no se graduó
- ☐ Graduado de la escuela secundaria o GED (Desarrollo Educativo General, por sus siglas en inglés)
- ☐ Algo de universidad o diploma de 2 años
- ☐ Graduado de una universidad de 4 años, o
- ☐ Diploma universitario de más de 4 años

32. ¿En qué condado vive ahora?

(Marque una respuesta).

- ☐ Baker
- ☐ Benton
- ☐ Clackamas
- ☐ Clatsop
- ☐ Columbia
- ☐ Coos
- ☐ Crook
- ☐ Curry
- ☐ Deschutes
- ☐ Douglas
- ☐ Gilliam
- ☐ Grant
- ☐ Harney
- ☐ Hood River
- ☐ Jackson
- ☐ Jefferson
- ☐ Josephine
- ☐ Klamath
- ☐ Lake

- ☐ Lane
- ☐ Lincoln
- ☐ Linn
- ☐ Malheur
- ☐ Marion
- ☐ Morrow
- ☐ Multnomah
- ☐ Polk
- ☐ Sherman
- ☐ Tillamook
- ☐ Umatilla
- ☐ Union
- ☐ Wallowa
- ☐ Wasco
- ☐ Washington
- ☐ Wheeler
- ☐ Yamhill

¡Gracias por sus comentarios!

Devuelva la encuesta en el sobre con franqueo pagado adjunto.